

# HIV: Challenging the Health Care Delivery System

## ABSTRACT

HIV offers a lens through which the underlying problems of the US health care system can be examined. New treatments offer the potential of prolonged quality of life for people living with HIV if they have adequate access to health care. However, increasing numbers of new cases of HIV occur among individuals with poor access to health care.

Restrictions on eligibility for Medicaid (and state-by-state variability) contribute to uneven access to the most important safety net source of HIV care financing, while relatively modest discretionary programs attempt to fill in the gap with an ever-increasing caseload. Many poor people with HIV are going without care, even though aggregate public spending on HIV-related care will total \$7.7 billion in fiscal year 2000, an amount sufficient to cover the care costs of one half of those living with HIV. But inefficiencies and inequities in the system (both structural and geographic) require assessment of the steps that can be taken to create a more rational model of care financing for people living with HIV that could become a model for all chronic diseases. (*Am J Public Health*. 2000;90:1033–1036)

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It has been said that HIV is a lens through which the underlying problems of the US health care system can be examined. While this has probably been true since the beginning of the epidemic in the early 1980s, now—nearly 20 years later—the response to the evolution of the HIV epidemic, particularly in terms of financing and care delivery, makes the United States' Rube Goldberg approach to providing health care even more apparent.

With promising new treatments for HIV, the model of care delivery has shifted from one of terminal care to one of chronic disease management. This does not necessarily mean that the new treatments known as highly active antiretroviral therapy are a cure, but the length and quality of the lives of people with HIV have been extended significantly.<sup>1,2</sup> Indeed, as death rates decline (e.g., a 42% decline between 1996 and 1997, followed by a 20% decline between 1997 and 1998<sup>3</sup>) and new infection rates appear to be holding constant (at an estimated 40 000 infections each year<sup>3</sup>), the total number of people who need care for HIV at any one time is increasing significantly, placing an additional burden on the health care system, primarily the publicly financed health care system. There are an estimated 800 000 to 900 000 people<sup>3</sup> living with HIV in the United States, of whom almost 300 000 are living with AIDS.<sup>4</sup>

### The Impact of New Treatments

Despite these positive trends, significant challenges to treating HIV remain. Moreover, as the demographics of HIV have shifted to those who have less access to care, the challenges of getting treatment for HIV have increased. In fact, the evolving demographics of those infected with HIV or at risk for HIV represent perhaps the most important factor related to access to care in the United States today.

People with HIV or at risk for HIV infection are increasingly likely to be poor and are usually members of racial/ethnic minority groups. Together, African Americans and Latinos represent the majority of new AIDS cases and of persons living with AIDS.<sup>4</sup> Women are also experiencing rapid rates of increase in HIV infection. Whereas in 1986, women represented only 7% of new AIDS cases,<sup>5</sup> they now represent almost one quarter

(23%)<sup>4</sup>; of those, 55% are young women aged 13 to 19 years.<sup>4</sup> In addition, the epidemic persists among gay and bisexual men of color, injection drug users, youth, and residents of inner-city urban areas.

These populations are all among the most likely to be without a regular source of care, to face barriers to accessing care, and to be dependent on the public sector for the financing and delivery of their care. Estimates of those who are on public insurance (Medicaid and Medicare) or are uninsured range from 68%<sup>6</sup> to 83%.<sup>7</sup> In addition, studies indicate that African Americans and Latinos with HIV/AIDS may be more likely than Whites to be tested at a later stage in the illness<sup>1,8,9</sup> and less likely to receive recommended HIV/AIDS therapy.<sup>10</sup>

### The Challenges of Treating HIV

It is in this context that the following challenges of treating HIV must be considered. First, the use of highly active antiretroviral therapy requires an individualized approach to treatment regarding when to start therapy, which combination of drugs is appropriate for an individual patient, when to switch drugs if the initial combination is not (or is no longer) effective, and so forth. This requires access to providers experienced in treating HIV. Numerous studies associate access to an experienced HIV provider with better health outcomes.<sup>11–14</sup>

Second, highly active antiretroviral therapy is very costly. The estimated cost of drugs alone for this therapy is \$10 000 to \$12 000 per year, which does not include the underlying costs of office visits and blood tests to monitor the effects of the drugs (although these costs are marginal relative to the actual costs of drugs). The durability of

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the treatment effect of highly active antiretroviral therapy is not yet known, and thus it is not known whether these additional prescription drug costs are replacing very high treatment and hospitalization costs often associated with end-stage AIDS or merely delaying them. Because it is recommended that highly active antiretroviral therapy be initiated relatively early in the progression of the disease,<sup>2</sup> this regimen has added costs to the front end of HIV, where once there were relatively few costs.

Third, the regimen involved with highly active antiretroviral therapy is complex, requiring patients to take many pills at different times each day, often with different requirements in regard to food intake. Adherence to the prescribed regimen is critical; it has been found that nonadherence leads to viral resistance, rendering the treatment ineffective and raising the public health threat of potential transmission of multi-drug-resistant HIV.<sup>1</sup> This makes the provision of adherence services that will help individuals sustain the treatment regimen prescribed a new and critical HIV-related care service, one not yet clearly integrated into the care system (and even less incorporated into the financing reimbursement system).

In addition to the challenges of the treatment regimens themselves are the limitations of the current public financing and care delivery system and of its capacity to address the complex needs of a growing population in need of HIV-related care.

### *The Impact of the Medicaid System*

Medicaid is the principal source of care financing for people living with HIV in the United States. The Office of Management and Budget has estimated the federal share of Medicaid spending for HIV at \$2.2 billion for fiscal year 2000. With state matches, this brings total Medicaid spending to about \$4 billion. And yet, the structure and policies of the Medicaid program often make it a challenge for people living with HIV to access the standard of care that includes treatment early in disease progression.

Most people with HIV gain eligibility for Medicaid by being both poor and disabled (in short, qualifying for Supplemental Security Income after having developed full-blown AIDS and becoming severely disabled). Thus, it is very difficult for those who are poor and have early HIV disease to use the nation's principal system of poverty-based care financing to access treatments that are purported to delay onset of disability. They are then dependent on other safety net programs,

such as the Ryan White CARE Act's AIDS drug assistance programs (discussed later), for accessing these treatments.

Unlike Medicaid, AIDS drug assistance programs (and all of the CARE Act programs) are not entitlements; they have limited funding appropriated each year. Even in instances in which access to drugs can be achieved through these programs, an individual with HIV must first have access to underlying primary care, so that a clinician can perform blood tests and prescribe medicines based on those tests. Again, unlike Medicaid, most of the CARE Act programs are not designed to provide a comprehensive set of primary care services, and thus AIDS drug assistance program beneficiaries are not necessarily assured access to the full system of comprehensive care services that are essential to highly active antiretroviral therapy.

Therefore, if they are unable to access AIDS drug assistance programs, poor people living with HIV will have to wait until their HIV becomes so severe that they are disabled. They will enter the Medicaid system sicker than their counterparts who have accessed highly active antiretroviral therapy through other means, and their care will be more costly to the public system as well.

One state, Maine, has received approval from the Health Care Financing Administration (HCFA) to expand its Medicaid program to those with HIV who are poor and not yet disabled, so that they can benefit from early treatment. HCFA sets a very high standard for such expansions, requiring that states show that interventions would be budget neutral over a 5-year period. With new treatments whose effects over such a time period are unknown, this can be quite a challenge.

To achieve budget neutrality, Maine had to set limits on the number of people who would be permitted to enter the expansion program, thus rationing care in a way that Medicaid generally does not. Even with this limit, Maine was able to achieve neutrality only by gaining commitments from pharmaceutical companies for significant drug discounts. HCFA's approval of the waiver is dependent upon the actual implementation of these discounts. Whether other states that represent much larger markets will be able to accomplish the same reduction in prices is unknown.

Recent social policy changes have also affected access to Medicaid for people who are at risk for HIV infection or have already acquired HIV. Welfare reform has reduced the overall number of Medicaid beneficiaries in many states, reducing the number of nondisabled poor women on Medicaid, a group facing one of the most rapid rises in HIV cases. Legislation that removed substance abuse as a

disabling condition has probably had an effect on the number of HIV-positive injection drug users who might have had earlier access to HIV-related treatment, although this effect has not yet been measured.

Because Medicaid is a state-run program, each state has its own approach to the administration of Medicaid within the parameters set by the federal government. This creates tremendous variation on a state-by-state basis in eligibility criteria and benefits. Thus, in the case of 3 HIV-infected individuals who live in 3 different states but have the same set of medical and financial circumstances, the first might have access to a comprehensive set of services, the second might be eligible only for minimal services, and the third might find himself or herself totally ineligible for Medicaid.

The state-by-state variability applies in almost every aspect of the Medicaid program, beginning with eligibility determination. In data provided to Rep Henry Waxman (D, Calif), the ranking minority member of the House Government Operations Committee, the Social Security Administration disclosed that there is tremendous variability among claims adjudicators in denial rates for those seeking an HIV-related disability determination (K. Apfel, Commissioner of Social Security, written correspondence to Rep Henry A. Waxman, May 1998).

In addition, only 34 states have opted for a Medicaid-administered program for the medically needy that permits disabled persons who are not poor enough to qualify for Medicaid's disabled category (in most states, 75% of the federal poverty level) to "spend down" onto Medicaid by deducting medical expenses from their income. Even in states with programs for the medically needy, there is tremendous variation in income thresholds, from as low as 25% of the federal poverty level in Arkansas to 86% in California.<sup>15</sup>

There is also variation in the benefit structures of state Medicaid programs. For example, in the critical area of prescription drugs, some states offer unlimited access, while others place limits on the number of prescriptions that can be filled in a month.

It also appears that Medicaid beneficiaries with HIV are not necessarily finding ready access to experienced providers. In October 1999, HCFA, citing a study<sup>9</sup> that showed that Medicaid beneficiaries were less likely to receive the necessary standard of care, called on state Medicaid programs to ensure access to experienced HIV providers in both the fee-for-service program and managed care.<sup>16</sup>

The shift of many Medicaid programs to managed care poses special challenges for people living with HIV. Will the provider net-

works of managed care organizations have experienced HIV providers? Will the states as purchasers require the managed care organizations to engage in prevention activities (in which the system benefits financially but an individual managed care organization may not, because of the relatively short period of time a beneficiary is part of one plan)? And will states provide the necessary capitation rate to make it financially feasible for managed care organizations to provide the standard of care and the continuum of support services that are considered essential to the successful implementation of that standard? (For examples of language designed to ensure quality in managed care purchasing, see material from the Center for Health Services Research and Policy.<sup>17</sup>)

## Medicare

Medicare, which has also become an important source of care for people with HIV, is now estimated to cover almost one fifth of people with HIV<sup>2</sup> and represents the second largest share of federal spending on HIV care (\$1.7 billion in fiscal year 2000, according to the Office of Management and Budget), after Medicaid. However, eligibility for Medicare among most people with HIV is similarly limited to those who are fully disabled and who qualify after being eligible for Social Security Disability payments for a 2-year period. Medicare is thus also limited to people who have sufficient work histories to qualify for Social Security Disability Insurance benefits. Medicare beneficiaries with HIV/AIDS are more likely than Medicare beneficiaries overall to be eligible for Medicaid as well<sup>1</sup> (also based on data from the HIV Cost and Services Utilization Study; D. Goldman, RAND, written communication, July 1999).

## The CARE Act

In 1990, Congress passed the Ryan White Comprehensive AIDS Resources Emergency Act (the CARE Act) by an overwhelming margin. It was reauthorized in 1996 with similar levels of support. The CARE Act was originally designed to mitigate the disparate effects of AIDS on the safety net providers in certain communities. It has since evolved into an almost \$1.6 billion program offering medical and social services for people living with HIV and at risk for HIV. These services are offered through various mechanisms, including the AIDS drug assistance programs mentioned earlier (which had a more than \$665 million budget,

from federal and state sources, in fiscal year 1999<sup>18</sup>). Congress is currently debating the second reauthorization of this program.

The CARE Act programs themselves are responding to the same challenges that the HIV epidemic is posing to the health care system in general—adapting to changing demographics, accommodating more clients as death rates decline, shifting from a death and dying model of service delivery to one that focuses on chronic disease care and management—all while trying to fill in the gaps in benefits offered Medicaid beneficiaries (such as social services that are considered essential to successful use of the medical system for those with HIV but are often not covered by Medicaid programs) and in eligibility criteria. (Thus, for example, the AIDS drug assistance programs provide drugs for those who are not yet eligible for Medicaid because they are not sufficiently disabled or because they do not meet stricter income criteria.)

But a national discretionary grant program, most of whose funds are distributed on a formula based on number of AIDS cases, cannot make up for the state-by-state variation in the Medicaid and safety net programs. In a sense, the CARE Act reinforces that variability: states with weaker Medicaid programs must spend more of their CARE Act dollars filling in gaps for populations that in other states would be receiving those services through Medicaid. In the states with strong Medicaid programs, CARE Act funds can be used to expand benefits or allow for broader eligibility criteria and thus cover more people.<sup>19</sup>

Addressing these discrepancies in the context of the CARE Act's reauthorization is something that policymakers have been wrestling with but not necessarily resolving. As an example of the challenge this issue poses: Should CARE Act dollars be targeted toward states with weaker Medicaid programs? Or would that be punishing states that have already stepped up to the plate to strengthen their Medicaid programs? In

short, a relatively small (relative to Medicaid spending) discretionary program cannot hope to resolve the inequities in the policies and administration of a much larger entitlement program.

It is important to note that the “traditional” discretionary safety net programs also stand beside the HIV-specific CARE Act. The nation's community health centers, for example, serve a large number of people living with HIV, sometimes with additional funding through Title III of the CARE Act, sometimes only with their regular health center grants (and any third-party reimbursement they can get). There is a certain irony in the fact that the health centers, which are designed to be the safety net providers for poor people in the United States, have a current appropriation of \$1.024 billion, smaller than the amount devoted to the CARE Act (almost \$1.6 billion), which is designed to serve only those with HIV disease.

## Resources Available for Care

It is relatively easy to see that, taken individually, each of these programs has limitations in regard to serving as a true safety net for people living with HIV, and it is therefore easy to understand that many people living with HIV are going without the care that they need. But when taken as a whole—when all of the resources in the various programs serving people with HIV in the United States are taken together—the inability to access appropriate care and services highlights the irrationality of the system we are using.

As Table 1 indicates, public spending in fiscal year 2000 on HIV-related care and services will total more than \$7.7 billion (excluding state spending other than the Medicaid match). By any reckoning, this is a significant amount of money. If we assume that 400 000 people with HIV (of the estimated 800 000–900 000 in the United States) depend exclusively on the public sector for their care, there

**TABLE 1—Estimated Public Spending on HIV-Related Care: United States, Fiscal Year 2000**

Program	Amount, \$
Medicaid (federal share)	2 200 000 000
Medicaid (estimated state share)	1 800 000 000
Medicare	1 700 000 000
Ryan White CARE Act	1 599 546 000
Veterans Administration	417 000 000
Total	7 716 546 000

*Note.* Data were derived from Office of Management and Budget fiscal year 2001 budget documents.



would be, on average, about \$19250 available on a per capita basis, more than the estimated \$18960 average annual cost of care for HIV (based on data from the HIV Cost and Services Utilization Study; G. Joyce, RAND, written communication, July 1999).

Why, then, are these resources, which seem to be sufficient overall to meet the care needs of people in the public sector, not doing the job? One reason is that national estimates do not necessarily reflect the resources available in every jurisdiction. Also, many programs that finance care for people living with HIV have multiple administrative structures at the national and state levels. (In addition to Medicaid and Medicare, the CARE Act alone supports 5 different funding streams for accessing services.) This complex infrastructure, while permitting providers to patch together appropriate care and services for a person with HIV, also creates inefficiencies and administrative costs. Furthermore, both Medicaid and Medicare have eligibility restrictions that usually limit enrollment until late in disease progression, when costs are highest. This combines to form a patchwork quilt of services that works well for some people but leaves others—based on geography or status—out in the cold.

## Incremental Steps

Clearly, if we as a nation embraced universal access and coverage for health care, people with HIV would not be facing the challenges they are in accessing care. This universal access could well be offered to people with HIV at little or no additional cost, given the funds being spent on supporting multiple funding streams. But comprehensive health care reform is not on the national agenda. The voters and Congress have been consistent in wanting the system to work better but not wanting to make radical changes. Incrementalism, even if it tends to create more complexities and perhaps even more inequities and irrationalities, is the only option on the table.

It is through our response to caring for people living with HIV that we can test some of these incremental steps, including the integration of funding streams into a more rational system of care delivery that emphasizes

early intervention or Medicaid expansion, through state-by-state demonstration programs, to people with HIV before they are disabled. Because HIV continues to be a major public health problem, and because of the political organization that has occurred around this epidemic, the political process is willing to provide additional resources to design a more comprehensive system of care for people living with HIV.

Does this represent HIV exceptionalism? Yes, in a sense: exceptionalism that permits the modeling of incremental, and possibly systemic, reform of the entire safety net system. The challenge for those working on these issues is to keep the eye on both prizes: improving health care access for people living with HIV while also developing models that will improve access for all who are dependent on the publicly financed safety net for their health care. □

## Contributors

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